

# Kith & Kids

autumn 2012



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## editor's notes

Hello! We know it's been a while since the last Readabout and there is plenty of news to tell so here goes. We have had a busy few months with 2:1 Social Development Project, Summer Camp, Residential Project and all our term time activities too. Particularly exciting are the variety of healthy activities we are running this term. And it's not just taking part in sports we've been doing, some of us even went to the Paralympics (find out more on page 9)!

We've also had some changes in the Kith & Kids staff team since you last heard from us. We'd like to welcome Becky Green as Project Coordinator. We are very happy to have her and she has already got stuck in with Summer Project, Camp, Club Sessions and Monday Socials. Also Scarlett Tozner-Milne has joined us (some of you may remember has already featured in this illustrious rag with an article about camp) as our projects intern until the end of the year. Whilst we've welcomed new members to the team we've also had to sadly say bye to two wonderful interns, Kate Caryer and Claudia Bonny whose hard work and commitment were much appreciated. See page five for an article by Kate about her time here.

Kith & Kids has always been diverse in the range of abilities and disabilities in its families. Now in our 43rd year there is also a wide range of ages and it brings into focus how needs change in different stages in life. We are very grateful to Jean Willson for sharing with us her experience, thoughts and feelings of how she and her family are dealing with Victoria's transition into the final stage of life. Thank you Jean for this enlightening and moving article.

We hope you enjoy the read and please do look out for upcoming events and activities we have coming up.

Thanks!

Maithi

## Life transitions by Jean Willson

Born in 1970 with the whole range of Tuberous Sclerosis Complex, so bad that the doctors would not even give a life expectancy, now aged 42 with her kidneys failing; major seizures, infections, and very poor health her tiny body worn out, and now, it seems, she is nearer her final transition, death. However, her family, her friends and her staff team want to share with you what we have planned so that we will give our remarkable and lovely woman Victoria her final transition without pain, with dignity and peace and lots of love in the most positive way we can for a much loved woman.

As a family, it was very difficult to face the facts that late last year, Victoria was becoming increasingly frail, and taking longer to rally after set backs in her health. As her mum, I went to a conference on Palliative Care for People with Learning Disabilities, and this set me thinking. I talked through where Victoria was at with Irene Turffey-Wijne afterwards about when would be the best time to call in the Palliative Care Team? She was very clear and said "do it tomorrow, often family carers have said to me: I wish I had done this earlier." Victoria had an appointment with her consultant in the Renal Unit the next day and he immediately set the ball rolling.

The very word 'Palliative' has dire overtones and something that I had been blocking, I think for sometime. When her consultant reacted as if he had been waiting for us to come to this conclusion, doubly re-affirmed that this whole business *was real* and Victoria could indeed, not be here! Then we had to go back to our family of just one – her elder sister, and her Circle of Friends and tell them of this future HUGE life transition stage.

Words cannot describe how we felt, but our overriding passion, determination and focus, *then* and *now* is that the quality of life for Victoria must be of the very best. After all, this is such an exceptional woman who has achieved so much throughout her life as a role model, activist, campaigner and trail blazer, as well as a much loved daughter, sister and close friend, that she deserves the very best we can get for her. Expecting the usual battles, blocks and barriers when facing another life transition for Victoria, imagine then our complete surprise when we had our first meeting with Barbara her first Palliative Team nurse, just four days after the hospital referred her. Barbara came to the house, went straight to Victoria touched her arm said hello etc. and said to her that she was here to make sure she was going to be comfortable and without pain. She was like a breath of fresh air, and so refreshing liberating, it was a huge relief to know that Victoria was going to be in safe hands. She checked out about talking things through in front of Victoria, and with that set the whole tone for the next few months of planning.



Victoria has lived safely and happily in her own home, with 24 hour support, for the last 21 years. It was, and is, essential that all the team, which includes the family and friends, work together, so it was at this stage with Barbara that we shared our plans for Victoria not to go to hospital and not be resuscitated. (We had gone through this with various medical emergencies over the years, and it had taken us a long time to come to this decision)

Barbara was amazed at how far we had planned things, and it was so re-assuring that she could now take the plans, give them medical authority and really make things happen. For example ensuring that ambulance people know that Victoria will not be admitted to hospital; that the emergency doctors know there is an End of Life Plan. And this was put into place immediately. I can't express her staff team's and the family's relief at this!

Over the months now, the Palliative team has helped Victoria's team with anything we present to them i.e. responding to Victoria's ever changing needs, like ensuring that pain killers are now given on a daily basis and anti-sickness medication is in the house. Problem solving with some medics who fail to believe her End of Life plans. Re-assuring us and explaining to us all the stages that Victoria might go through, and how she must feel. We, in turn, are able to explain to Caitlin (her new nurse) how Victoria might react. Caitlin is also cascading out through Islington and Camden, information about supporting someone with PMLD's. Over the months, Victoria is getting even more tired; and the episodes of nausea/diarrhea are increasing. The frequency and strength of her seizures are also increasing. But an unidentified infection which led to her refusing food was treated, and she has slowly come back, a little bit like her old self. Encouraging Victoria to eat and drink takes lots of imagination and patience. Pacing her moods and ability to do things takes an enormous amount of skill and attention to detail. Ensuring her flatmate is aware of what's going on, but making sure she still does what she loves to do. All of these things her staff do exceptionally well and positively.

We, her family have been making sure the bungalow is bright and looking good. Arranging and bringing Victoria visitors who have known her for years for brief visits. She seems to enjoy these visits, as we sit round her chatting and talking about her music.

Victoria has always struggled to make herself understood, and we often wonder what she would be saying to us now at this time. All we know is that we have done the very best we can to make sure our lovely daughter is without pain, supported by a terrific staff team who know what she wants and when. That her family and friends are going to be there with her.

# family support news

Our family support team is keen to do more and more outreach to help families who aren't necessarily involved with Kith & Kids. Helen R and Helen H are going back to WAVE in Muswell Hill (an inclusive youth group) to do some games and activities to help the group continue to bond. Carol And Helen H are off to the American Institute of Foreign Studies to train their staff to support students who have autism and or learning disabilities who are away from their home countries. We hope that the experience that our team have gained over the years can be shared and be of help to others.

## Pampertastic!

A great afternoon of massage, pedicures, manicures, stunning cakes and chat was had by all at the parent pamper afternoon. There was a lovely mix of new and old Kith & Kids parents chillaxing together. A special thanks to Rebecca and Amelia for volunteering their skills and time as therapists. We will definitely be doing the afternoon again and plan to make it a regular feature on parents' Kith & Kids calendar.

## Respite Weekends

It feels incredible that we are about to embark on our sixth respite weekend away, marking the last weekend of the year for us. We really have got into a good rhythm now, with certain features becoming regular, if not obligatory! For example having a camp fire and telling jokes or silly stories whilst supping on hot chocolate ... name tags on bunk beds ... and farmyard activities! I do wonder what some parents must think of all of the photos and animal stories that accompany their son or daughter home! A particularly surreal moment for me last weekend was watching ferret-racing at the one and only Buckinghamshire Goat Centre!



The last weekend we stayed at Dell Farm again which – as well as being able to collect fresh eggs in the morning – provides us with a great semi-professional kitchen to work in. Next weekend we are trying out a new venue – and quite a different style of weekend – by visiting a PGL activity centre, where lots of activities for the members will be provided on site. With one new member joining us, this will be yet another different weekend which we are all looking forward to. We'll let you know in the next issue how we got on!

*Helen Robertson*

## parent bulletin • things to do & read...

### Kith & Kids Themed Parent Meetings:

#### **Saturday 24th November: Getting the best out of Social Services Assessments**

Hugh Constant (Social Care Institute for Excellence [SCIE])

#### **Sunday 9th December: Supporting your son or daughter with their sexuality**

Speaker TBA

### Helpful links

Lots of helpful links to places to help keep people with Learning Disabilities and/or Autism safe whilst using the internet.

<http://www.choiceforum.org/docs/isafe.pdf>

Netbuddy's new 'Info Pack' with lots of tips around the area of Transition (which may or may not be pertinent to you - but feel free to share around your contacts), including a fantastic poster which is great to print out and have as a reference point .

The pack can be found at: <http://www.netbuddy.org.uk/info-packs/transition/>



# an intern's experience at K&K

Hello, Kate Caryer here. I was a projects intern at Kith & Kids from March to July. The experience has been the most exciting, challenging (at times frustrating) thing I have ever done. Nonetheless, I wouldn't change it for the whole world.

Let me explain; I have pretty significant cerebral palsy. That means that in my case I can't walk properly, I need a communication aid and my hands don't work very well but I have grown up expecting to do what everyone else does. So when the time came to think about work, I thought I would work. Then I saw an advert for this opportunity to be a projects intern here. I knew of Kith & Kids for being a disabled person around North London and my mates were siblings of members and volunteers.

I thought I would get an application form and try to do it (my first job application ever!). I did and for some reason, sent it off. That was okay because my ever supportive mother said I would probably not get it. Very quickly, I saw I got an email from a guy called Robin asking for me to come to an interview with him and Miles (my first job interview ever!). I said, "Yes". Soon, the day of the interview came. I was nervous but that was all right but just before I went out the door my lovely mum said, I probably won't get it.

To my surprise, the interview went well. We were really honest about stuff I might find challenging due to my disability. The interview was an experience in itself because it was my first one ever! Robin and Miles were fantastic at accommodating me and my needs while being fair to the other candidates for the internship.

Soon after the interview, I was offered the post! I was ecstatic! However, Robin said it would only work if we were honest with each other and he and Kith & Kids were willing to give it a try if I was up to it. So in March I started working at Kith & Kids. It was good to work in an office with lovely people that know about disability. However, for mixed reasons, it was not the wonderful thing we had hoped. Firstly, the difficult bit was the type of work: inputting data, sending lots of emails and doing mail shots and my dodgy hand function were not a match made in heaven. I use personal assistants (people to enable and support me with anything I do), so I took them to work, it was like "take your assistant to work day" everyday! It is fair to say I have had a few hit and misses with using assistants in the office and communicating with them in my time with Kith & Kids. It is something I have to work on in any future job. This made me feel sad and made me question my ability to work but I think I could do a lot of other stuff.

Despite these difficulties and hard times, I had some brilliant and fun experiences with the brilliant organisation which is Kith & Kids. Let me share my top five Kith & Kids moments:

- i. I loved coming to projects and club and seeing members and volunteers working and having fun together.
- ii. It was brilliant to see volunteers developing through training and working with members. I remember the first volunteer I played the warm up games with at the last training before Easter and seeing him again in May supporting a profoundly disabled man well.
- iii. I am not usually one for walking in rain but one Monday (anyone who says they don't like Mondays should come and hang with those guys!) with the Monday Social group, we were walking back to the Irish Centre from the school where they cooked yummy food and we had fun and a certain young man took it upon himself to make sure I was all right in my wheelchair. We were running and he was directing me and we had great fun.
- iv. Remember the comedy program 'The Office'? But working at Kith & Kids office is funnier. Some members of staff can give comedians a run for their money!
- v. I would like to say that one of the best things about Kith & Kids is that they believed in me, especially Robin, even when times were rough. Robin and I had a few difficult chats as well as brilliant ones, during those times he was honest and never ever patronising me saying everything was fine when it was actually not.

Thank you Kith & Kids but it is time to move on.

# OUR PROJECTS



## Social Development Project

During the last week of July and the first week of August there was a spectacular and inspirational event happening in London. No, we aren't talking about the Olympics - 2:1 of course! Once again, we gathered at Northumberland Park School to have two weeks of fun and creativity. Thanks to all the workshopers who got everyone involved in music, art, craft, drama, video, dance and massage.

Apart from getting involved with all the workshops, the Youth Group focused on hobbies and did presentations to the others on their favourite activities. And what a diverse group they are; there were descriptions of horse-riding, pencil sharpening, walking along the beach and even a full-on reenactment of the witches' scene from Macbeth!

Everyone also went out on outings around London. There were visits to comic book shops and Covent Garden including the "best fish and chips and ice cream ever!" Other outings included going to the science museum, M&M world, inclusive cycling in Finsbury Park, Boris-biking around London and Hamley's took a special interest, setting aside a whole room full of toys for Kith & Kids!

Of course throughout the project there was plenty of delicious food provided by the parents and volunteers in the kitchen so thanks to all of you who helped keep everyone fed and happy!

The end of projects show told a swash-buckling story about three nasty pirates (a workshoper, volunteer and dad) who had to be vanquished by some very brave Kith & Kid-ers. As usual the show encompassed all the hard work that had been done throughout the two weeks, exhibiting some truly spectacular scenery and masks from art and crafts. Plus there was plenty of music and dance with even an impromptu and inclusive choir performance led by a member of the youth group who demonstrated one of the choir warm-up songs (Poppy-cat-a-petal...know it?) Overall, a wonderful end to the project. A special thanks to all the volunteers who came and added a great energy to the project.





## Summer Camp

What a great success camp was once again. It's always a wonderful time a year when a group of 70 or so participants who have a disability, volunteers and staff get to go away for eight days to the field centre in Surrey. It most certainly is one of the highlights of the Kith & Kids calendar, and this year was no disappointment.

There were of course the regular staples of K&K Summer Camp: campfires, the scary night walk, rafting, outings to Brighton and walks along the pier and just a general sense of fun. There really is something about getting away from the city that brings everyone together!

There were also plenty of other exciting activities to keep the holiday-goers entertained. There was a game-show night where everyone took part in thrilling (and often competitive) versions of Family Fortunes, Generation Game and Play Your Cards Right. And, to add bucketfuls of glamour into camping (I believe it's called glamping!) we had a fashion show too which would have given Paris, Milan and London a run for their money.

Of course, although away from London, it was near impossible to completely ignore the Olympics and so we had our version which included the most difficult sports of all i.e. human skittles, high jumps, welly-wanging (for those of you who haven't done this, trust us, it's brilliant!) and much more. And there were plenty of cheers and medals for all!

In order to feed all this activity each group cooked for each other, and made it even more exciting by having a theme each night, including Moroccan, pub, pirate, spooky and Hawaiian luau! It was like going to a different exotic restaurant each night! And of course the food was most certainly up to standard. All of this wouldn't have happened without the volunteers, group leaders and staff so thanks everyone!





# adult services

## Residential Project

On the first week of August (6-10 August), 11 participants of the Employability and Life Skills Project along with volunteers and Rich and Jay returned to Whitwell Hall in Norwich. This time, as a new development, half of the group took the train there and back. It worked really well, apart from being a lot cheaper, the group really enjoyed the independence and the joys of travelling by train.

The theme of the project was evaluating the progress of each individual participant since the first residential in Spring 2010. Many were amazed at how much change and achievement there had been in the lives over the last couple of years including starting work, moving out of home and starting college courses as well as leaps in confidence. In light of this, the group discussed what they would like to learn on future residentials to continue their development.

One of the key aspects of the Residential Project is that each member of the group runs their own session. This includes planning for it before and running it on the project itself. Once again there was a wide variety of activities reflecting their diverse hobbies and interests! There was breadmaking (proving useful on the journey home), a quiz, an energetic games workshop, storyboarding, song survey, t-shirt and stone painting, dancing, drama games and a session on the meaning of lyrics! It's amazing that there were able to fit it all into four days! Plus the group went on a nature walk and had to make meals for themselves too! A particular highlight was making a card for Alex and his family as they welcome Stanley (their newest member!) into the world.

The group look forward to the next residential which will be taking place in Kent.





# term time activities

## ELSP (Employability and Life Skills Project)

ELSP has started again this term, now offering up to five days a week for those who would like to use their personal budgets to purchase a place on the project. The project looks at developing skills for work, further study as well as for greater independence. We are very excited by this expansion and look forward to seeing ELSP develop and meet new people.

## Healthy Activities

In our last newsletter we mentioned that we had started inclusive healthy activities in The Irish Centre. Those who take part are young adults with learning disabilities or autism, volunteers, staff and other people in the local community. The sessions are open to all so please do get in touch with Alex on 0208 801 7432 or alexm@kithandkids.org.uk to come along.

## Yoga and Bokwa - Fridays, 2-3pm

This term we have had yoga and bokwa (a form of zumba) sessions on Friday afternoon, which has really pushed our group to the limits (learning exactly how flexible they are!).

## Kith & Kids United (our very own football team!) - Wednesdays, 6.30-8.30pm

We also have a football team who meet every Wednesday evening. The team have really hit it off and are getting ready for a football tournament on the 19th November organised by Navigant. Special thanks to Karen Bond, Paul Rodwell and Jehan Sherjan for putting lots of hard work in to get it organised. And thanks to Eddie for donating a kit and making the team look very professional. Please come and support our team at their first ever tournament at **Tottenham Powerleague, Willoughby Lane, N17 OSL, 7-9pm!**

## Monday Socials

The Monday Socials have returned with a bang in the autumn term. The group are slowly growing and already this term have had music, comedy, cooking and games sessions. They look forward to getting involved in many more activities in the weeks to come.

# paralympics 2012

We won 40 tickets to the Paralympics through their Community Scheme and what a fantastic experience it was for all involved.

Everyone met at 9am at Stratford Station to collect the tickets from Helen R and Danielle. Armed with tickets, enthusiasm and excitement the Kith & Kid-ers went on to the Olympic park which proved to be even more grandiose than expected; the excitement and camaraderie of all the spectators was palpable to all. Some went to the swimming whilst others managed to wangle their way into basketball and handball.



All in all everyone went home pretty exhausted but equally happy with a truly memorable experience. Thanks to everyone who organised the day! Here's a couple of quotes...

"Me and my brother Sam went to watch the swimming which was fun. It was a really good view even though we had to climb so many stairs to get there! Later we hung out at the park, had lunch and went home. Really happy that I got to see the Olympic Park which I wouldn't have the chance to otherwise!" - Ben Parker

"We just didn't want to leave - the atmosphere was so brilliant" - Mary and Allison Roseweir

# FUNDRAISING

It's probably no surprise to you that it is becoming increasingly difficult to secure funding for our activities and services. At the same time, we are aware that our projects are needed more than ever due to reductions in services elsewhere. We have made some inroads due to very good news from the Big Lottery Fund who have awarded us £277,000 to be spent over three years on social development, friendship and healthy living activities. We must also thank The Gatsby Charitable Foundation for £5000 and The Baily Thomas Charitable Fund for £10,000. However, as we are determined to keep delivering all of our current projects, we still have a long way to go and need your help more than ever. We'd like to make a special mention to those individuals who have fundraised for us and will hopefully inspire you to do the same!

- Those who donned their trainers and ran the British 10K or Royal Parks Half Marathon.
- The London Marathon Team who have raised a whopping £51,000! As a team they went well over their target and we are extremely thankful for all their hard work.
- Cedric Bardawil who has organised two art events called "Something in the Attic", displaying and selling original art by local artists. They have kindly donated a percentage of their profits to Kith & Kids and have so far raised over £900
- Nick Yates, Jonny Muir, Tom Levitt and William Surman who took it upon themselves to do the challenge of all challenges. They travelled from London to Paris by foot, boat and bicycle over the course of two days; running a distance of 100 miles in relay from London to Dover, rowing a boat to cross 22 miles of The English Channel to Calais and then cycling 180 miles to Paris. From their own admission it was an exhausting feat but one they all managed to complete as well as raising over £1000 for Kith & Kids!
- Other individuals who have asked for their birthday and wedding presents to be donations, who have skydived, ran and collected at supermarkets (amongst other activities) all to raise money for Kith & Kids. We won't tire of saying this - every bit does count!



## The Holiday Season!

The festive season is soon upon us and if you want to avoid the mad crowds start early! Thankfully we have a special Xmas shop full of gifts and cards for you to give your loved ones. Visit [www.kithandkids.org.uk](http://www.kithandkids.org.uk) to see the full range. Plus we have a couple of exciting seasonal events for you to come along to!

### Xmas Cards & Gift Voucher Cards

We have a lovely range of Xmas card this year so get in touch with us and we'll can get them delivered to you. A pack of 5 cards (including festive envelopes) for £3.50. You can also buy a gift voucher, giving a donation to our Xmas Project.

### Carol Sing-along!

We are having a special festive sing-song featuring the Kith & Kids choir. There'll be mince pies too! Please let us know if you can come. Sunday 9th December, 4:30 - 5:30pm at Ermine Road Day Centre.





## Ride London 2013

Brought to you by the same people who run the world-famous London Marathon, Ride London 100 is its cycling equivalent. Aiming to be the largest charity cycle race in the world with 20,000 participants, Ride London 100 will begin at The Queen Elizabeth Olympic Park and finish in central London on the Mall. Riders will cycle 100 miles and have to finish the event in under 9 hours. It's all taking place on Sunday 4<sup>th</sup> August and will be part of a two-day festival of cycling which includes an elite cycle race on the same day. This new and exciting event celebrates the legacy of London 2012 and promises to be a spectacular day.



So here are the facts:

**Date:** Sunday 4<sup>th</sup> August 2013

**Distance:** 100 miles

**Route:** Starts at Olympic Park, through city, Surrey Hills and finishing on the Mall.

The roads will be closed off.

**Time:** 6am-8am (depending on ability and fitness)

**Registration Fee:** £50

**Minimum sponsorship:** £600

Get in touch with Maithi on 0208 885 1517 or [maithi@kithandkids](mailto:maithi@kithandkids) for more information!

## Santa 5K

This is your chance to dress up as Santa and take a 5K stroll or mad-dash through a park. The purpose of this run is not to win but take part and get silly – oh and raise lots of money for Kith & Kids too.

This fun run is the perfect way to kick-start the festive season so get together a team of friends, family and colleagues! And you get your Santa costume for FREE – what more can you ask for?

**Date:** 9th December 2012

**Reg Fee:** £20

**Distance:** 5K or 10K

**Minimum Sponsorship:** £100

**Location:** Greenwich Park

## London Marathon 2013

We are very pleased to say that we have filled all out marathon places - yes we welcome 30 runners to our special Kith & Kids team! So thank to all of you who are training and raising money for us this year. The money that you raise will go towards our summer activities in 2013.

We'd also like any of you who know people who are running the marathon, or if you are yourself, and who don't have a charity to run for to come along to us. Even if you have a place already, running as a part of team makes a big difference and helps motivate you on those rainy mornings when running for 6 miles just doesn't seem that appealing. Plus on the day we cheer you on and have a lovely party afterwards with a massage! You can't ask for more than that!

# kith & kids agm

On the October we held our AGM at the Irish Centre. There was a good turnout, with presentations from Ed Hurren (chair) and Ralph Rosen (treasurer) as well as an outline of the year from Marjolein de Vries. Thank you to everyone who came especially for the discussion at end regarding possible ideas for new avenues of income.



## dates for your diary

**Football Tournament** (19th Nov) 7-9pm - Tottenham Power League, Willoughby Lane, N1 0SL- come cheer us on!

**Jazz Night** (30th Nov) 7-9pm at The Irish Centre - a KLASP fundraiser with fabulous music all evening.

**Festive Sing Song** (9th Dec) 4:30-5:30 at Ermine Road - songs, mince pies and general festivity!

**Santa 5K Run** (9th Dec) - a walk or run around Greenwich Park!

**Xmas 2:1 Social Development Project**  
(27-31 Dec)